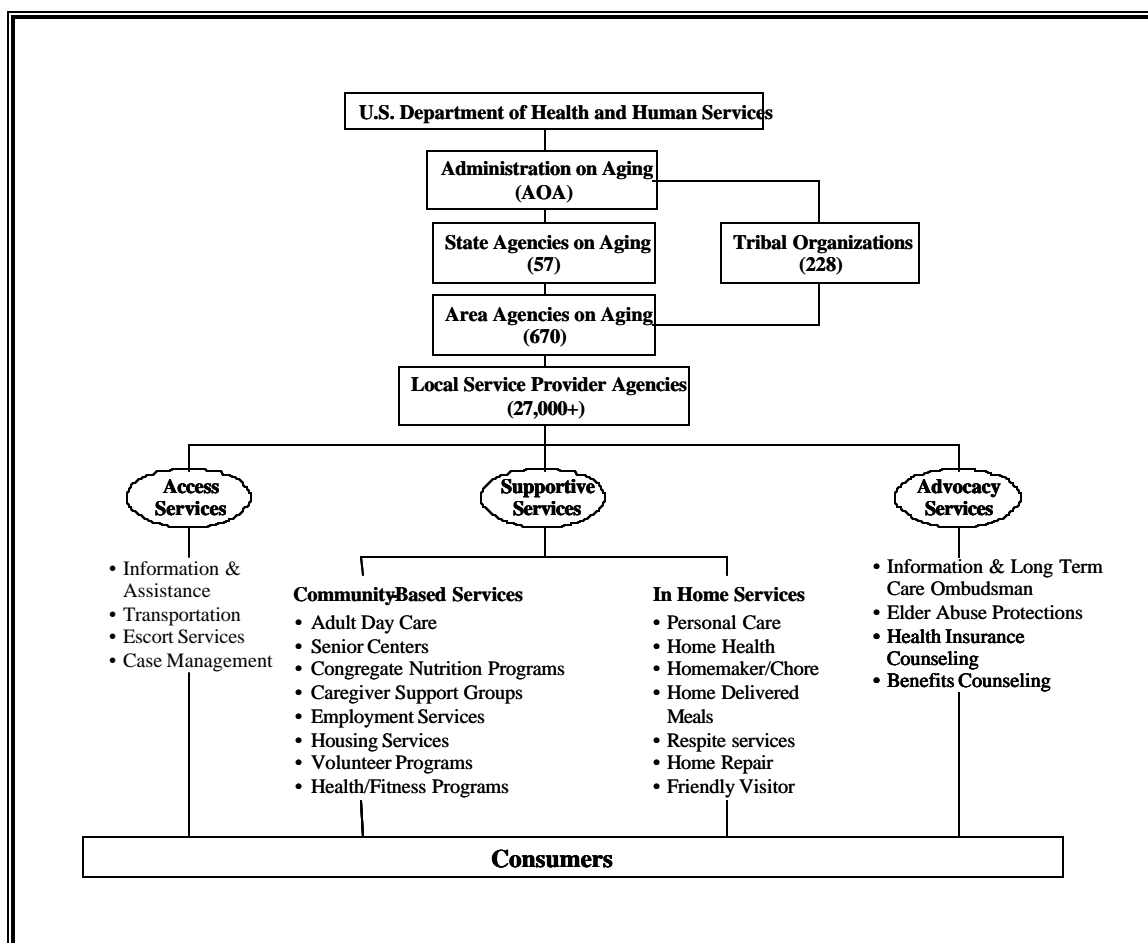


II. ROLES OF THE AGING NETWORK

This chapter details the primary roles of the aging network as they relate to the National Family Caregiver Support Program (NFCSP). Under the authority of the Older Americans Act (OAA), the Administration on Aging (AoA) works closely with other partners in the national aging network to plan, coordinate, and provide home- and community-based services (HCBS) to meet the unique needs of older persons and their caregivers. The aging network includes AoA, 56 State Units on Aging (SUAs), 655 Area Agencies on Aging (AAAs), 233 Indian Tribal Organizations (ITOs) representing 300 American Indian tribes, two organizations serving Native Hawaiians, plus thousands of service providers (SPs). *Exhibit II.1* provides an overview of the aging network before the enactment of the NFCSP.

Exhibit II.1
Network on Aging (OAA Structure Chart)



Source: The National Association of State Units on Aging.

Agencies of the aging network may be involved in policy development; service system development; advocacy at the system, program, and consumer levels; service provision; and management. However, AoA, SUAs, AAAs, ITOs, and SPs will have varying degrees of responsibility for each of these activities.

Service provision is a good example. While AoA has no direct role in providing services, SUAs and AAAs may have a limited role. Under the OAA, they can provide direct services if the SUA determines: 1) it is necessary to assure an adequate supply of services; 2) the service(s) is directly related to SUA or AAA administrative functions; or 3) SUAs or AAAs can provide comparable quality more economically. In some states, SUA and AAA staff carry out functions that range from information and assistance (I&A) to care management for OAA programs as well as state-funded and Medicaid HCBS programs. However, in most cases, SUAs and AAAs provide services indirectly, coordinating programs, identifying gaps and weaknesses in services delivery, and directly funding local agencies that actually provide the services required. On the other hand, nearly all ITOs deliver services directly and all SPs do so.

The NFCSP not only adds a sizeable new categorical program for the aging network to administer, it also adds a new priority population to take into account. Thus, the program provides the network agencies an opportunity to re-examine how they carry out their overall roles and responsibilities, particularly in relation to implementing the NFCSP.

ADMINISTRATION ON AGING

Under the NFCSP, AoA, through its central office staff and nine regional offices, performs a number of tasks, including policy development, technical assistance, research and demonstrations, and systems development.

AoA issued program guidance to initiate program implementation and first-year reporting requirements and will issue both regulations and ongoing reporting requirements for the NFCSP. Measures used in the National Aging Program Information System (NAPIS), including those for the NFCSP, are currently under review by AoA and a workgroup of aging network representatives.

AoA has provided technical assistance through a number of activities, including:

- Establishing a technical advisory group (TAG) comprising researchers and aging network representatives who informed the content of this Resource Guide and advised on other AoA technical assistance activities;
- Creating a Web page devoted to the NFCSP;
- Commissioning more than 20 issue briefs from prominent researchers and staff of the aging network and posting them to the NFCSP Web site;
- Sponsoring the September 2001 *National Family Caregiver Support Program: From Enactment to Action* conference at which more than 700 participants exchanged information and generated new ideas;

- Organizing a structured listserv to disseminate research-based information and to generate the exchange of information among network staff; and
- Commissioning this Resource Guide, which brings together information gained from all of the above activities in a practical, easy-to-use format.

AoA also is administering the National Innovation Program under the NFCSP (see *Appendix B* for Fiscal Year 2001 awards) and is engaged in systems development work related to caregivers with other federal agencies (e.g., Centers for Medicare and Medicaid Services [CMS] and the Office of the Assistant Secretary for Planning and Evaluation [ASPE]), and national organizations.

STATE UNITS ON AGING

A state's governor designates a state government agency as the SUA to serve as the focal point for all matters relating to older persons within the state. SUAs are located within a multipurpose state agency, such as a department of family services or human services, or their own independent, single-purpose agency, such as a department on aging or commission on aging. SUAs are responsible for ensuring effective implementation of the NFCSP broad policy objectives.

In brief, SUA functions include:

- **Management and Administration.** With input from the AAAs' local plans, advisory bodies, and consumers of services, SUAs develop a state plan inclusive of the NFCSP. SUAs also assume the primary role for the development of an intrastate funding formula (IFF), approving AAA area plans, and monitoring the activities and expenditures under the approved area plans.
- **Service System Development.** SUAs develop a state-level multi-faceted service system in keeping with the NFCSP and integrate this system into the social and health services system for older persons. *Exhibits II.2 and II.3* summarize two states' approaches to service system development. *Exhibit II.2* shows Washington's program requirements and guidance conveyed to the AAAs regarding the NFCSP. Just before the passage of the NFCSP, Washington had a fledgling caregiver support program. As a result, the state had to cope with the challenge of blending Title III-E requirements and funds with other funding sources. *Exhibit II.3* illustrates how North Carolina took a fresh perspective on the caregiver program development.
- **Services Development.** SUAs set policies on quality assurance, provide guidance, and facilitate information exchange among AAAs to make resources available that help shape services development in the state.
- **Advocacy.** SUAs identify areas in which caregiver support programs might need legislative support and might advocate greater state funding. SUAs also advocate for programs with other public agencies and private organizations and promote caregiver support programs with the public at large.

Exhibit II.2 Washington Aging and Adult Services Administration Role in NFCSP Implementation

Title: Washington SUA Approach

Affiliation: Washington Aging and Adult Services Administration

Status: Operational

Approach: The Washington SUA saw its role as shaping local processes rather than prescribing the exact way in which AAAs should provide services. An existing state funded Respite Care program and state funds during the previous year for their Family Caregiver Support Program influenced policy decisions in the development of the National Program. The SUA role included developing a framework for and facilitating discussions with AAAs, distributing materials to AAAs, and expecting that AAAs develop a multifaceted system rather than focus on one specific service category. To do so, the SUA limited funding for respite to 35 percent. In addition, the state required AAAs to develop NFCSP plans that demonstrate how the federal funding will allow them to do something new and that addresses each of the five core service categories.

Contact Information: Hilari Hauptman, Program Manager, Washington Department of Social and Health Services, Aging and Adult Services Administration at haupthp@dshs.wa.gov or (360) 725-2556; Lynne Korte at kortelm@dshs.wa.gov or (360) 725-2545.

Exhibit II.3 North Carolina Department of Aging Role in NFCSP Implementation

Title: North Carolina SUA Approach

Affiliation: North Carolina Division of Aging

Status: Operational

Approach: The North Carolina SUA encouraged each AAA to hire a regional caregiver specialist to lead in leveraging resources, developing partnerships, identifying and supporting critical needs, expanding successful services, and evaluating the program to guide its future direction. The SUA is encouraging specialists to develop a comprehensive system of services that includes each of the five core service categories. To avoid duplication of efforts and ensure cost-effectiveness, the specialists are partnering with many different organizations, including the regional Alzheimer's chapter, vocational rehabilitation's Independent Living Program, social services, support groups, Cooperative Extension, mental health, hospice and end-of-life care, respite care providers, and local lead agencies for planning home- and community-based services. The SUA is also collaborating with AARP and the Duke Family Support Program. To promote a continuous exchange of ideas with regional specialists, the SUA arranged through the University of North Carolina for bimonthly videoconferences between the SUA and the AAAs. The two-hour videoconferences include equal thirds of information sharing, training opportunities, and technical assistance, offering a great opportunity for SUA staff to hear AAA concerns and provide guidance on program development.

Contact Information: Chris Urso, Family Caregiver Program Specialist, North Carolina Division on Aging, at chris.urso@ncmailnet or (919) 733-8400.

AREA AGENCIES ON AGING

AAAs are public or private nonprofit agencies designated by SUAs to carry out the OAA at the sub-state level. AAAs assume many of the same broad responsibilities as the SUA—management and administration, service system development, services development, and advocacy—but focus more on the local area and on direct involvement in services development and delivery. In the 13 states designated as single planning and service areas (PSAs), the SUAs carry out the functions of both the SUA and AAA. AAAs can be public agencies located within county governments, a regional planning council, a unit of city government, an office within an educational institution, or an independent nonprofit organization.

How AAAs carry out their role in implementing the NFCSP likely will be heavily influenced by their role relative to other OAA functions. For example, needs assessment, contract development, and monitoring will be foremost for AAAs that primarily fund providers to deliver services. For AAAs more active in service delivery, e.g., provision of information and referral and care management by in-house staff, issues regarding staff development, assessments, and service coordination might be of primary concern. AAAs at both ends of the spectrum will benefit from improved understanding of caregiver needs and strategies for meeting their needs.

Exhibits II.4 and II.5 summarize two AAAs' approaches to service development. *Exhibit II.4* explains the approach of Senior Spectrum, a Maine AAA that also administers the assessment and care management functions of the Medicaid Home- and Community-Based Waiver (HCBW). This AAA chose to have one person become the caregiver specialist for both I&A and care management and also encourage innovative approaches by community organizations through competitive grants. *Exhibit II.5* describes the plans of a Minnesota AAA that primarily contracts out most services to develop services otherwise unavailable.

Exhibit II.4

Senior Spectrum Role in NFCSP Implementation

Title: Developing Community Partnerships

Affiliation: Senior Spectrum (AAA, Maine)

Status: Operational

Approach: Senior Spectrum supplemented existing services rather than built an entirely new caregiver infrastructure. The AAA hired one fulltime family caregiver specialist to present information about caregiving and the NFCSP to the public, facilitate relationships with businesses, work with two advisory councils, and develop marketing materials. In addition, the AAA hired a family caregiver coordinator to conduct one-on-one outreach to caregivers, in person and over the telephone, and work with support groups. The coordinator examined existing support groups to determine the style and content of each for referral purposes. If no group meets a caregiver's need, the AAA plans to create additional support groups in such a way that caregivers can take over the group and call on the AAA only when they need support. In addition, the AAA created a seed money fund to support collaborations with community organizations or businesses for effectively identifying and providing resources to caregivers in their community. The AAA targeted specific organizations, including home health agencies and boarding homes, and placed a notice in the daily news asking interested parties to respond to a request for collaborations (RFC). The AAA selected four of eight applicants based on their plans to meet documented guidelines, reach caregivers, staff tasks, meet reporting requirements (which include a one-page progress report halfway through the year-long grant and a two-page final report), build capacity, and sustain the collaborative relationship beyond the seed money. A total of \$5,000 was set aside for the fund. Awarding grants of \$500 to \$2,500, the AAA fully funded three organizations and partially funded a fourth.

Contact Information: Debra Halm, Senior Director, Senior Spectrum, at dhalm@seniorspectrum.com or (800) 639-1552 ext. 119; Leslie Shaffer, Senior Spectrum, at lshaffer@seniorspectrum.com or (800) 639-1552 ext. 106.

Exhibit II.5 Minnesota AAA Role in NFCSP Implementation

Title: Planning and Collaboration

Affiliation: Region Nine Development Commission AAA, Minnesota

Status: Developmental

Approach: The State of Minnesota's Long Term Care Task Force included supporting the informal network of caregivers as one of its six policy recommendations for reshaping the long term care system. This particular AAA has organized a stakeholder group including caregivers; providers of adult day services, nursing homes, and home health agencies; members of advisory boards; and nurses to help identify priorities for NFCSP funding and provide guidance on AAA requests for proposals (RFPs). In-home respite was identified as one of the greatest unmet needs in the AAA's regional analysis, compiled from the legislatively mandated county gaps analysis. The AAA is striving to expand its role beyond the allocation of funds by offering technical assistance and best-practice information to agencies that serve caregivers, providing materials to distribute to caregivers, and recognizing and supporting caregivers. Finally, the AAA hopes to develop caregiver support and volunteer respite services in the unserved areas of their region, forming a region wide support system for caregivers.

Contact Information: Linda Giersdorf, Director, Region Nine AAA, at lindag@rndc.mankato.mn.us or (507) 389-8866.

INDIAN TRIBAL ORGANIZATIONS

ITOs, comprising Indian tribes, Alaska Native villages or corporations, and organizations serving Native Hawaiians, provide the overall leadership for implementation of the Native American Caregiver Support Program (Title VI-C) and the Native American component of the NFCSP. Through Title-VI programs, ITOs provide multifaceted systems of support services for family caregivers and for grandparents or older individuals who are relative caregivers. ITOs take on the same broad responsibilities as both SUAs and AAAs. In addition to management and administration, service systems development, service development, and advocacy, ITOs provide direct services.

A major challenge for ITOs in implementing the new program involves development of core services. Unlike other communities, many Indian communities lack services, such as home health, adult day services, hospice, and support groups. If services are available in neighboring non-Native American communities, ITOs might consider developing relationships with the providers in these communities and assist in making their services culturally appropriate.

SERVICE PROVIDERS

All local SPs concerned with older persons should consider their role in NFCSP implementation. AAAs will fund some SPs directly. These and other SPs and community organizations might consider serving as a potential referral source as they identify a caregiver in need, raising public awareness of caregivers, offering support groups, training caregivers, or generating funds to supplement caregiver programs. AAAs can

foster this type of service development through small service development grants, training providers, regular information exchange meetings, or co-location of services. **Exhibit II.6** outlines a faith-based organization's development of a program to support Jewish caregivers, and **Exhibit II.7** details a nonprofit organization's efforts to offer comprehensive services to caregivers. **Exhibit II.8** describes how a provider has used OAA dollars through a contract with the state of New Jersey SUA to offer a statewide respite program to local caregivers.

Exhibit II.6 **Faith-Based Organization's Potential Role** **in NFCSP Implementation**

Title: As Families Grow Older

Affiliation: Winter Park Health Foundation, Grotta Foundation

Status: Operational

Approach: Grotta Foundation's use of Winter Park Health Foundation's As Families Grow Older (AFGO) curriculum, which consists of a six-part volunteer- and clergy-facilitated workshop, is designed for use by faith communities to educate congregations and the wider community about the aging and caregiving processes. It includes a hands-on planning and program guide; technical assistance materials on volunteer recruitment, training, program publicity, and outreach; and a series of user-friendly participant workbooks to help families make informed choices when dealing with eldercare challenges.

Contact Information: Cathy Michaelson Lieblich, Miller Center for Older Adult Services, at clieblich@wphf.org or (407) 629-5771; See the description in *Caregivers Loss: Family Needs Profession Responses*, Hospice Foundation of America (2001), pages 153–156.

Exhibit II.7 **Nonprofit Community Organization's Role** **in NFCSP Implementation**

Title: IONA Senior Services Adult Day Health Center and Caregiver Support Groups

Affiliation: IONA Senior Services, Washington, DC

Status: Operational

Approach: IONA's Adult Day Health Center, a medical model program, assists medically frail older adults having cognitive or physical limitations with a stimulating environment of activities, including Tai Chi, weight lifting, music, art, and pet therapy. The Center provides a place of respite to families responsible for caregiving. The program employs a fulltime nurse to monitor medications, communicate with physicians, and provide support and guidance to caregivers. IONA also sponsors caregiver support groups for adult children caring for older relatives. The six-week sessions are open to family members of participants in the Adult Day Health Center as well as to the larger community.

Contact Information: Mary Ann Fiske, Information and Assistance Coordinator, at mafiske@iona.org or (202) 895-9448. Visit IONA's Web site at <http://www.iona.org/index.html>.

Exhibit II.8 Provider's Potential Role in NFCSP Implementation

Title: Statewide Respite Program

Affiliation: Visiting Nurse and Homemaker Services, Division of Senior Affairs (SUA), New Jersey Department of Health and Senior Services

Status: Operational

Approach: Visiting Nurse and Homemaker Services, under a three-year contract with the state of New Jersey SUA, provides a respite program to financially eligible caregivers. Referrals for caregivers in need come from hospitals, social services, and caregivers themselves. The program serves individuals with liberal eligibility criteria, allowing individuals and couples to possess up to \$40,000 in liquid assets. Services are delivered in the following ways: in-home services, funding for medical or social ADS, private duty nursing, companion services, temporary respite in institutional settings, and alternate family care. Alternate family care offers short-term placement for the older adult in the home of a New Jersey resident who is willing, trained, and approved to offer temporary respite.

Cost/Funding: The funding supports multiple salaries, including the director, field nurses for assessments, and a financial person. Visiting Nurse and Homemaker Services sponsors the program in two counties with grants: Burlington (\$245,180) and Gloucester (\$153,385). Seventy-five percent of funds support direct purchase of services and the remaining 25 percent support administrative costs.

Contact Information: Bonnie Mangle, Director of Special Programs, Visiting Nurse and Homemaker Services, at bonnie_mangle@toadmail.com or (609) 267-7417.